

Supplemental Materials

Supplemental Table 1. Respondent country during COVID-19 survey II (May 2020, $n = 391$)

Country	<i>n</i> (%)
United States	285 (72.9%)
United Kingdom	31 (7.9%)
Canada	17 (4.4%)
Australia	14 (3.6%)
Germany	8 (2.1%)
France	4 (1.0%)
Ireland	4 (1.0%)
Netherlands	3 (0.8%)
Spain	3 (0.8%)
Israel	2 (0.5%)
Sweden	2 (0.5%)
Austria	1 (0.3%)
Brazil	1 (0.3%)
Bulgaria	1 (0.3%)
Cyprus	1 (0.3%)
Greece	1 (0.3%)
India	1 (0.3%)
Italy	1 (0.3%)
Macao	1 (0.3%)
Mexico	1 (0.3%)
New Zealand	1 (0.3%)
Norway	1 (0.3%)
Poland	1 (0.3%)
Portugal	1 (0.3%)
Puerto Rico	1 (0.3%)
Russian Federation	1 (0.3%)
South Africa	1 (0.3%)
Suriname	1 (0.3%)
Switzerland	1 (0.3%)

Supplemental Table 2. Dependent's genetic status (*n* = 319)

Genetic Status	<i>n</i> (%)
16p11.2 deletion	71 (18.2%)
SCN2A	30 (7.7%)
16p11.2 duplication	24 (6.1%)
GRIN2B	21 (5.4%)
ASXL3 (Bainbridge-Ropers)	20 (5.1%)
PPP2R5D	20 (5.1%)
STXBP1	16 (4.1%)
1q21.1 deletion	13 (3.3%)
SYNGAP1	13 (3.3%)
CSNK2A1 (Okur-Chung)	12 (3.1%)
7q11.23 duplication	9 (2.3%)
DYRK1A	9 (2.3%)
1q21.1 duplication	8 (2.1%)
CHAMP1	8 (2.1%)
MED13L	8 (2.1%)
SETBP1 (Schinzel-Giedion)	8 (2.1%)
SLC6A1	8 (2.1%)
CTNNB1	7 (1.8%)
HIVEP2	7 (1.8%)
PACS1 (Schuurs-Hoeijmakers)	7 (1.8%)
16p11.2 deletion DISTAL	6 (1.5%)
ADNP (Helsmoortel-van der Aa)	6 (1.5%)
HNRNPH2	5 (1.3%)
TRIP12	4 (1.0%)
16p11.2 duplication DISTAL	3 (0.8%)
ARID1B (Coffin-Siris)	3 (0.8%)
CHD2	3 (0.8%)
PPP2R1A	3 (0.8%)
17q12 duplication	2 (0.5%)

ASH1L	2 (0.5%)
GRIN1	2 (0.5%)
GRIN2A	2 (0.5%)
KCNQ2	2 (0.5%)
KDM5B	2 (0.5%)
SETD5	2 (0.5%)
15q11.2 BP1-BP2 deletion	1 (0.3%)
3q29 deletion	1 (0.3%)
ANKRD11 (KBG)	1 (0.3%)
AUTS2	1 (0.3%)
BCL11A	1 (0.3%)
CASZ1	1 (0.3%)
CHD3	1 (0.3%)
CHD8	1 (0.3%)
CTBP1	1 (0.3%)
DNMT3A (Tatton-Brown-Rahman)	1 (0.3%)
FOXP1	1 (0.3%)
GIGYF1	1 (0.3%)
HNRNPU	1 (0.3%)
KMT2E (O'Donnell-Luria-Rodan)	1 (0.3%)
MBD5	1 (0.3%)
NLGN4x	1 (0.3%)
NRXN1	1 (0.3%)
POGZ (White-Sutton)	1 (0.3%)
PPP2R5C	1 (0.3%)
PTCHD1	1 (0.3%)
PURA	1 (0.3%)
SHANK3	1 (0.3%)
TAOK1	1 (0.3%)
USP9X	1 (0.3%)
VPS13B	1 (0.3%)

Supplemental Table 3. During COVID-19 some dependents required access to physicians and caregivers and responded if they received telehealth services, in-person at home services, in-person at the physician office or if they could not access these medical services ($n = 319$).

Physician	Needed to access <i>n</i> (%)	Accessed through - <i>n</i> (%)			
		Telehealth	At-home	In-person office	Could not access
General practitioner	116 (29.7)	67 (57.8)	1 (0.9)	42 (36.2)	6 (5.2)
Psychiatry	28 (7.2)	23 (82.1)	1 (3.6)	2 (7.1)	2 (7.1)
Neurology	66 (16.9)	52 (80)	0	5 (7.7)	8 (12.3)
Gastroenterology	33 (8.4)	20 (60.6)	0	2 (6.1)	11 (33.3)
Psychology	22 (5.6)	11 (50)	1 (4.6)	5 (22.7)	5 (22.7)
Other specialty	85 (21.7)	33 (38.8)	3 (3.5)	17 (20)	32 (37.7)

Supplemental Table 4. During COVID-19 caregivers reported if they postponed appointments or procedures for their dependents ($n = 319$).

	Yes <i>n</i> (%)	No <i>n</i> (%)
Appointments postponed	255 (65.22)	136 (34.8)
Procedures postponed	134 (34.3)	257 (65.7)